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Ethnic differences in cognition and age in people diagnosed with dementia: a study of electronic health records in two large mental healthcare providers

Running title: Ethnicity and cognition and age at dementia diagnosis

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Abstract

Objectives: Qualitative studies suggest that people from UK minority ethnic groups with dementia access health services later in the illness than white UK-born elders but there are no large quantitative studies investigating this. We aimed to investigate inter-ethnic differences in cognitive scores and age at dementia diagnosis.

Methods: We used the Clinical Record Interactive Search (CRIS) applied to the electronic health records of two London mental health trusts to identify patients diagnosed with dementia between 2008 and 2016. We meta-analysed mean Mini Mental State Examination (MMSE) and mean age at the time of diagnosis across Trusts for the most common ethnic groups, and used linear regression models to test these associations before and after adjustment for age, sex, Index of Multiple Deprivation and marital status. We also compared percentage of referrals for each ethnic group with catchment Census distributions.

Results: Compared to White patients (N=9380), unadjusted mean MMSE scores were lower in Asian (-1.25; 95% CI -1.79, -0.71; N=642) and Black patients (-1.82, 95% CI -2.13, -1.52; N=2008) as was mean age at diagnosis (Asian patients: -4.27 (-4.92, -3.61); Black patients -3.70 (-4.13, -3.27) years). These differences persisted after adjustment. In general, ethnic group distributions in referrals did not differ substantially from those expected in the catchments.

Conclusions: People from Black and Asian groups were younger at dementia diagnosis and had lower MMSE scores than White referrals.

Key words: dementia, ethnicity, diagnosis

Key Points

- Age at dementia diagnosis in UK South Asians has never been established
- In our cohort mean age at dementia diagnosis in White UK patients was 82 years
- Black and Asian patients were diagnosed around four years earlier than White patients
- Black and Asian patients has lower cognitive score at diagnosis

Background

There are over 46 million people living with dementia worldwide and this costs the global economy \$818 US dollars.¹ The number of people with dementia is expected to increase to 131 million by 2050 and its associated costs are expected to exceed \$1 trillion by 2018. This upward trend in numbers of people with dementia will continue, mainly because of increasing life expectancies.² Although there are no disease-modifying treatments for dementia, medications and interventions can help alleviate the symptoms, and there are possible strategies for prevention.³ Diagnosis is the gateway to services such as accessing support for family carers, optimising safety, and making decisions about future care as well as addressing medico-legal issues while the person with dementia retains the ability to do so.⁴ Consequently, many countries are taking steps to improve timely diagnosis of dementia and in the UK this has been a key focus of the National Dementia Strategy.⁵

The UK has sizeable minority ethnic populations, together accounting for 15% of the English population and around 40% of the London population.⁶ Minority ethnic populations in the UK are younger than the majority population but are predicted to increase in the next 10 years, as is the proportion of older people within these populations.⁷ The prevalence of dementia in minority ethnic groups will therefore increase. Thus any difficulties of access in minority ethnic groups to dementia diagnosis and care is becoming more important and there is growing impetus to address disparities in these areas.⁸ A systematic review and meta-analysis found that worldwide, people from minority ethnic groups with dementia accessed healthcare services in the later stages of their illness, were less likely to be prescribed cholinesterase inhibitors and less likely to take part in drug trials.⁹ People from minority ethnic groups are also less likely to be formally diagnosed with

dementia, and are more likely to obtain the diagnosis following a crisis.¹⁰ These factors are likely to have a negative impact on outcomes in these populations. However, few studies that have evaluated whether minority ethnic groups present to dementia diagnostic services in sufficient numbers, or the severity of cognitive impairment at initial presentation. African-Caribbean people have a higher prevalence of dementia compared to the White British population.¹¹ One small London-based study found that people from African-Caribbean backgrounds are on average 8 years younger when diagnosed with dementia compared to the White population and have lower scores on cognitive testing, indicating more advanced disease at presentation.¹² There are no studies of age of dementia onset or severity at diagnosis for minority ethnic South Asian populations.

Minority ethnic populations are well represented in referrals to memory services, indicating that these populations are accessing services, but there has been no evaluation of the stage of severity of cognitive impairment at presentation.^{13, 14} There has been an increase in the number of people diagnosed with dementia since the launch of the National Dementia Strategy in 2009¹⁵ but evaluation of the effect of this policy has not specifically investigated dementia diagnosis among minority ethnic groups; nor has there been quantification on a large scale of any differences in dementia severity between different ethnic groups at presentation to memory services.

In the study described here, we used routinely collected data from two large mental healthcare providers to examine the age at diagnosis and degree of cognitive impairment among different ethnic groups presenting to memory services. We hypothesized that people from minority ethnic groups would be younger, but would have a greater level of cognitive impairment, as measured by standardised cognitive

tests, compared to the White British population. We also investigated whether Black and Minority Ethnic (BME) groups are well represented in referrals to dementia diagnostic services for older adults.

Methods

Settings and participants

We used the Clinical Record Interactive Search (CRIS) system to obtain data for this study. The CRIS system is a platform developed to enable searches in anonymised routine electronic health records based on an explicit de-identification process.¹⁶ We used data from two large mental health trusts. The South London and Maudsley NHS Foundation Trust (SLAM) is a large secondary mental health provider serving a catchment area of four inner-city and outer-city boroughs — Croydon, Lambeth, Lewisham, and Southwark—with a total population of around 1.36 million residents.¹⁷ Camden and Islington NHS Foundation Trust (C&I) provides mental health services to two inner-city boroughs (Camden and Islington) with around 440 000 residents.¹⁸ Ethical approval to use CRIS at South London and Maudsley NHS Foundation Trust was received from the Oxfordshire Research Ethics Committee C (08/H0606/71+5); approval to use CRIS in Camden and Islington was received from the National Research Ethics Service Committee East of England—Cambridge Central (14/EE/0177). All memory services provide access to specialist diagnostic and treatment services. Assessment of patients is by qualified staff using standardised and validated cognitive tests.

We searched CRIS for patients with a recorded diagnosis of any type of dementia from 1st January 2008 to 31st October 2016 in C&I and from 1st January 2008 to 31st July 2016 in SLaM.

Measures

Mental health diagnoses: Diagnoses made in UK secondary care are routinely recorded using International Classification of Diseases (ICD-10) criteria. We derived dementia diagnoses using ICD-10 codes F00 to F03 (Alzheimer's disease, vascular dementia; Dementia in other diseases classified elsewhere and unspecified dementia), and G30 for early onset Alzheimer's disease.

Ethnicity : We used self-defined ethnicity categories as used in the UK National Census.⁶ There are 11 main categories, but we combined all South Asian ethnicities into an Asian subgroup, all Black ethnicities into a Black subgroup, all Mixed ethnicities into a Mixed subgroup and defined all remaining ethnicities as Other.

Area-level social deprivation: The Index of Multiple Deprivation (IMD) combines national census information from 38 indicators into seven domains of deprivation (income; employment; health and disability; education, skills, and training; barriers to housing and services; living environment; and crime).¹⁹ This results in one deprivation score for 32,482 'lower super output areas' in England, geographical units used for the reporting of neighborhood level statistics. Each area has an average population of around 1500 people (about 400 households). Patients' addresses are recorded in routinely collected clinical data. We obtained IMD scores by linking the lower super output area code of each patient's permanent address to 2011 national data. Higher IMD scores indicate more deprived areas. IMD scores were classified into tertiles, with the lowest (least deprived) category the reference.

Cognitive impairment: The main outcome of interest was the first documented Mini Mental State Examination (MMSE) score in the patient's record.²⁰ The MMSE is a cognitive test in routine clinical use which has been extensively validated. It is scored out of 30, a score below 24 indicating significant cognitive impairment, with moderate dementia usually defined as a score of between 10 and 20 and severe dementia defined as a score of less than 10. In addition to structured fields from the source record, MMSE scores were extracted from text fields in the CRIS database using Natural Language Processing (NLP) algorithms, developed and evaluated for extracting knowledge from unstructured text data,¹⁷ specifically Information Extraction where unstructured text is converted into structured tables.¹⁷

Other demographics: We extracted data on age at dementia diagnosis, sex and marital status. We coded marital status as married, divorced or separated, widowed, and single (never married).

Analysis

We included all patients for whom there was a valid recorded diagnosis of dementia, ethnicity and MMSE. We calculated mean age at diagnosis and mean Mini Mental State Examination (MMSE) score for each ethnic group. First we conducted a univariable linear regression with first recorded MMSE scores as the outcome and ethnic group a six category exposure (reference category: White British). Next we adjusted this model for potential confounders: age, sex, IMD score and marital status. We repeated this procedures with age at diagnosis as outcome measure. Using RevMan software, we combined data on MMSE and age at diagnosis from the two NHS trusts in a meta-analysis, calculating mean difference between minority ethnic groups and the White British population.

In order to compare the ethnic group distributions in memory service attendees with those in the underlying population, we used the Greater London Authority population projections (<https://data.london.gov.uk/dataset/gla-population-projections-custom-age-tables>). These are estimated population numbers which are updated every year. We used the figures for the population over the age of 65 in each borough as we reasoned that this population would have a significant prevalence of dementia and 65 years is the usual minimum age of referral for patients to memory services. We compared ethnic group percentages in those seen by memory services in each borough per year with the source ethnic group proportions in the population. We applied this to years 2011 to 2015 as these years had complete information for referrals.

Results

We identified 13,233 (6.5%) people with a diagnosis of dementia during the observation period out of a total of 201,658 patient records in SLAM and 4684 (4.0%) out of 116,936 in C&I. In SLaM 11,169 (84%) and in C&I 4218 (91%) individual records had at least one MMSE data point available. Data on the exposure, ethnic group, were available for 10,941(98%) dementia patients with an MMSE in SLaM and 3864 (90%) in C&I. Data on a complete case sample, when all confounders were included, were available for 10,415 (93%) in SLaM and 3374 (79%) in C&I. Supplementary Figures 1 and 2 are flowcharts of how the final sample for complete case analysis was derived in SLAM and C&I respectively.

Supplementary Table 1 shows the demographic characteristics of people included and excluded from the analysis sample. We found no evidence of an association between ethnic group and missing data.

First recorded MMSE

Table 1 shows the mean differences in first MMSE between the White British population and other ethnic groups. Mean MMSE was 21.4 (S.D 5.9) for the White British population in C&I and 19.9 (S.D. 6.4) in SLAM. Mean MMSE was 18.3 (S.D. 6.3) in South Asians in C&I and 19.5 (S.D. 6.9) in SLAM and 18.4 (S.D. 6.2) in C&I and 18.3 (S.D. 6.5) in SLAM for Black patients. Asian and Black patients had MMSEs around 3 points lower than the White British population in C&I but only one point lower in the Asian population and 2 points lower in the Black population in the SLAM sample. Combining the samples in a meta-analysis, unadjusted mean MMSE scores were lower, indicating more severe cognitive impairment, in Asian (Pooled mean difference -1.25, 95% CI -1.79 to -0.71: N=642) and Black patients (Pooled

mean difference -1.82, 95% CI -2.13 to -1.52: N=2008). These results are shown in Figures 1 and 2. There was no evidence of a difference in the MMSE scores of the Mixed population compared to the White British population. We performed a sensitivity analysis, comparing MMSEs closest to time of diagnosis to see if the trends were different. Our sensitivity analyses found very similar results in mean MMSE at time of dementia diagnosis (Mean difference -3.28 (95% CI -4.22 to -2.35) in South Asians and -2.95 (95% CI -3.66 to -2.24) in Black people, compared to the White population), indicating that cognitive scores were lower in minority ethnic groups at diagnosis and that first MMSE was very similar to MMSE at age of diagnosis. [Place Figures 1 and 2 and Table 1 here]

Age at diagnosis

White British people were diagnosed at a mean age of 82 years. Black people were on average three years younger and Asian people were around four years younger than the White British population when diagnosed with dementia, as shown in Table 2. These results were similar across both NHS Trusts with meta-analysis of unadjusted mean ages showing an overall mean difference in Asian patients (N=642) of -4.27 years, (95% CI -4.92 to -3.61) and Black patients (N=2008) of -3.70, (95% CI -4.13 to -3.27) compared to the White British group (N=9380) as shown in Figures 3 and 4. The differences were more marked in C&I compared to SLAM (mean age at diagnosis 77.7 vs 82.0 for South Asians and 79.0 vs 82.0 for Black people in C&I compared to 77.4 vs 81.6 for South Asians and 77.7 vs 81.6 for Black people in SLAM). [Place figures 3 and 4 and Table 2 here]

Referrals

Supplementary Table 2 shows the percentage of referrals in each ethnic group and percentage in the underlying population in that borough for that year. Most boroughs show that a lower percentage of White British people were referred to services. Most minority ethnic groups were well represented, or any deficit in percentage of minority ethnic referrals was relatively small. There was no discernible pattern in the percentage differences over time. In SLAM, from 2012, services were re-structured so a significant proportion of older adults with memory problems were then referred to geriatric medicine services and referral percentages are therefore lower than might be expected.

Discussion

This is, to our knowledge, the largest study to investigate age and the severity of cognitive impairment at presentation to dementia diagnostic services across ethnic groups in different clinical settings. We found evidence that people in South Asian and Black minority ethnic groups were four to five years younger and scored two to three points less on cognitive testing at time of presentation compared to the majority population. These findings are similar to a previous study reporting earlier age of onset and lower MMSE scores in the Black population with dementia compared to the White British population. However, this is the first time these differences have been recorded for the UK South Asian population and the finding of an even younger age at dementia diagnosis and lower cognitive scores than the Black population is striking. The differences in age at diagnosis for minority ethnic groups were remarkably similar across both NHS Trusts, indicating that earlier age of onset of dementia is significant for both Black and Asian ethnic groups in the UK.

We could not adjust our estimates for languages spoken or level of education for included participants as this is not routinely collected data. However, we reasoned that as the diagnosis of dementia was made by trained professionals, it was likely to have taken language difficulties and differences in culture into account and the MMSE recorded for those diagnosed with dementia was therefore likely to be a reasonably accurate measure of cognitive impairment.

MMSE scores were significantly lower for minority ethnic groups in both NHS Trusts but this difference was smaller in SLAM compared to C&I, which may indicate a more educated population in SLAM or a population with better English language skills.

We have also examined whether referrals to memory services reflect the underlying population structure in terms of ethnic minority representation. Referrals from the White British population were generally lower than would be expected but we know from previous research²¹ that ethnicity tends to be least often recorded for people from the majority population so this may account for the apparent deficit. The finding that the percentage of people in each ethnic group generally mirrors the ethnic make-up of the underlying population is encouraging. However, as we know that Black Caribbean people in the UK have a higher prevalence of dementia with onset up to eight years earlier, we might expect referrals to be higher. We do not know the prevalence of dementia in the UK South Asian population. If it is higher than the White British population, these referral numbers may also be an under-representation. A previous population-level survey found that Black people were diagnosed with dementia on average eight years before the White population¹¹, but we found only a difference of around four years. This could indicate that the memory

service population is not representative of the population and that more needs to be done to encourage help-seeking in minority ethnic groups.

These findings have potential implications for clinical outcomes in dementia in minority ethnic populations and indicates an urgent need to address any barriers to help-seeking.

Strengths and limitations

We had access to a large number of participants from two different mental health trusts in geographically and ethnically diverse parts of London. Validity of dementia diagnosis has been shown to vary in different settings but dementia recorded in specialized secondary mental healthcare is generally considered to be “gold standard”, has very high specificity²² and takes into account cultural and language differences, especially in a diverse area such as London. In the UK, standard practice is for most people with cognitive impairment to be seen in memory clinics which are mainly in older adult psychiatric services so these patients will not necessarily be those with more behavioural disturbance. However, patients with young-onset dementia may be more likely to be referred to neurology services. We cannot make inferences about any differences in presentation to primary care or diagnosis in other settings. Although we could not adjust for language or education, two of the studies to find worse cognitive scores in minority ethnic groups presenting with dementia did adjust for education and still found a significant effect of ethnicity on cognitive score.^{23, 24} However, it is important to acknowledge that previous work in the Black UK population has found that population norms on the MMSE are lower than for the White British population²⁵, with the Afro-Caribbean population having a median of 25 and the white UK of 27 (although there was no difference in scores on

memory items) so it is possible that the lower MMSE scores are reflective of baseline differences and are not due to greater cognitive impairment. We could not explore health conditions or other possible causes for the observed differences as these data were not sufficiently well recorded but it is possible that it is due to genetic differences, the greater prevalence of vascular risk factors in Black and Asian groups,²⁶ or differences in smoking, alcohol use and education. Although there were missing data, the percentage was small. We may have missed people with more severe cognitive impairment or those for whom completing the cognitive testing was more of a challenge due to language difficulties; however, we think that this would dilute rather than exaggerate our observations. Commonly people from minority ethnic groups have been recruited in lesser numbers into dementia research but as our studies use anonymized data we do not have to rely on recruitment which may be biased. Additionally, the measurement of social deprivation used in this study relied on statistical data obtained from the Index of Multiple Deprivation, which relates to census information for the area in which the person lived rather than their personal circumstances, and therefore reflects the experience of living in an area of deprivation rather than personal deprivation experienced. It may be that the onset of dementia is earlier in minority ethnic groups so referrals for young onset dementia may be higher in this population but we cannot comment on this as we only looked at data for those over the age of 65. Although both NHS trusts studied were in London, they encompass 6 boroughs which are economically and ethnically diverse so the results are likely to be generalisable to the UK generally and may also be relevant to other countries with similar healthcare systems.

Conclusion

In this large sample we have identified that people from minority ethnic backgrounds have lower cognitive scores and are younger at first diagnosis of dementia than the White British population. There is a need to understand these inequalities, to see if dementia prevention initiatives should be tailored by ethnic group and to ensure dementia diagnosis across all ethnic groups is obtained as early as possible.

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Table 1. Association between ethnic group and MMSE scores in C&I complete case sample (N=3374) and SLaM complete case sample (n=10,415)

| | C&I | | SLaM | |
|---------------|--|----------------------------|--|----------------------------|
| | Mean difference in MMSE scores (95% confidence interval) p-value | | Mean difference in MMSE scores (95% confidence interval) p-value | |
| | Univariable | Adjusted for confounders* | Univariable | Adjusted for confounders* |
| Ethnic group | | | | |
| White British | Reference group | Reference group | Reference group | Reference group |
| Asian | -3.21 (-4.14 -2.29) <.0001 | -3.36 (-4.30 -2.42) <.0001 | -0.40 (-1.01 0.22) 0.206 | -0.90 (-1.51 -0.29) 0.004 |
| Black | -3.16 (-3.87 -2.46) <.0001 | -2.99 (-3.71 -2.27) <.0001 | -1.54 (-1.88 -1.19) <.0001 | -1.78 (-2.14 -1.43) <.0001 |
| White other | -1.78 (-2.28 -1.28) <.0001 | -1.75 (-2.25 -1.25) <.0001 | -2.36 (-2.90 -1.83) <.0001 | -2.47 (-3.00 -1.94) <.0001 |
| Mixed | -1.62 (-3.66 .42) .121 | -1.66 (-3.72 .35) .105 | -0.77 (-2.20 0.65) 0.288 | -1.12 (-2.53 0.29) 0.119 |
| Other | -1.78 (-2.92 -.65) .002 | -1.94 (-3.08 -.81) .001 | -1.22 (-1.87 -0.56) <.0001 | -1.34 (-2.00 -0.69) <.0001 |

*confounders were age at diagnosis, sex IMD tertiles and marital status.

Table 2. Association between ethnic group and age at diagnosis (continuous outcome) in C&I complete case sample (N=3374) and SLaM complete case sample (n=10,415)

| | C&I | | SLaM | |
|---------------|--|----------------------------|--|-----------------------------|
| | Mean difference in age (95% confidence interval) p-value | | Mean difference in age (95% confidence interval) p-value | |
| | Univariable | Adjusted for confounders* | Univariable | Adjusted for confounders* |
| Ethnic group | | | | |
| White British | Reference group | Reference group | Reference group | Reference group |
| Asian | -4.81 (-6.00 -3.63) <.0001 | -4.66 (-5.81 -3.50) <.0001 | -4.23 (-5.04 -3.41) <.0001 | -4.04 (-4.81 -3.26) <.0001 |
| Black | -3.48 (-4.37 -2.58) <.0001 | -2.67 (-3.56 -1.79) <.0001 | -3.91 (-4.37 -3.45) <.0001 | -3.30 (-3.75 -2.86) <.0001 |
| White other | -1.65 (-2.29 -1.02) <.0001 | -1.40 (-2.02 -.79) <.0001 | -1.04 (-1.75 -0.34) 0.004 | -1.26 (-1.94 -0.59) <.0001 |
| Mixed | -4.62 (-7.23 -2.01) .001 | -4.14 (-6.63 -1.64) .001 | -4.93 (-6.82 -3.04) <.0001 | -3.93 (-5.72 -2.14) <.0001 |
| Other | -4.05 (-5.50 -2.60) <.0001 | -2.93 (-4.32 -1.53) <.0001 | -1.63 (-2.50 -0.76) <.0001 | -0.77 (-1.60 0.06) 0.068 |

*confounders were sex, IMD tertile, MMSE scores, and marital status.

List of Figure legends

Figure 1: Mean MMSE differences in South Asian compared to White British patients

Figure 2: Mean MMSE differences in Black versus White British patients

Figure 3: Mean age differences at dementia diagnosis in South Asian compared to White British patients

Figure 4: Mean age differences at dementia diagnosis in Black compared to White British patients